

**White House Conference on Aging
Solutions Forum on Rural Aging
Radisson Hotel
Morgantown, WV
May 25, 2005**

Good afternoon. My name is Jane Marks and I am the Executive Director of the Alzheimer's Association West Virginia Chapter.

I want to introduce you to our friend "Louise" (not her real name). Following are excerpts from some of her e-mails to our Chapter. She is in her 70's and cares for her husband "Clyde"(not his real name) who has Alzheimer's. She and Clyde live in a rural county in southwestern WV. All of their children live far away. Louise is very proud and does not want to ask for help "Louise does not drive and refuses to discuss her "family problems" with others. Her sons thought she was much too isolated, so they purchased a computer and taught her how to use e-mail. Through the internet, she found us. Through us, she has an outlet for her frustrations, fears and questions.

**"At 11:30 tomorrow the Dr. is going to evaluate C for Medicaid.
Is that Welfare? I don't want to be on Welfare, bad enough to beg for
the Aricept, but it is \$138.00 for one month. Ouch! I called my son and
he said it wasn't begging, I should just tell the truth. Will they ask personal,
degrading things
to Clyde? I hope not.**

**Last night he slept his usual 40 minutes and was up raring
to go. Pulled all the socks out, tore up the toilet paper into tiny
exact piles. So neat. Then the miracle! I told him that I had forgotten
to give him his medicine. and I gave him one of the new sleeping tablets the
doctor gave me. He almost wouldn't take it, but finally did. In about 25 minutes
he was ready to go to bed AND SLEPT THENIGHT THROUGH! Now ain't that
grand? Everything is rosy. I'm a rosy person, I had a good nights sleep.**

These are some of the things I would like for you to learn.

**1. Why [in this disease] is there nothing ever constant? Once I get a
problem mastered and am patting myself on the back, it jumps to a higher
category?**

- 2. Why does someone so amiable of the day become so difficult at night?**
- 3. Why is a 12 hour night longer than a twelve hour day?**
- 4. Why is someone who used to be so clean now spitting in the floor?**

If this was a disease such as diabetes or cancer I think I could deal with it, but this thing sure has got me buffaloed. I need a starting point [solid]. One that I can depend on, one that is the same, at least 3 days straight. What works once doesn't work another.

You don' t really have to write back if you don't have time. It feels better just to write it down."

Clyde and Louise were turned down for the Medicaid waiver because the reviewer asked if Clyde could hold a fork. He can, but he does not know what to do with it. The reviewer asked if Clyde could go to the bathroom by himself. He can, but he may urinate on the floor, in the trashcan, or in the bathtub.

Louise began having her own health problems, severe stomach pain that she ignored for a long time. When the pain became debilitating she finally told the doctor. After many tests the doctor finally decided was stress related.

Louise is, unfortunately, quite typical of the Alzheimer's caregivers in WV and across the country. Based on the government definition of rural, nearly the entire state of West Virginia qualifies as rural. Our rough and mountainous terrain, and the cultural attitudes of our mountain people create a unique challenge for those of us concerned with rural health issues. Services that, on the map, as the crow flies, look accessible, are often only accessible via curvy mountainous roads, and travel time is lengthened when you can't fly like the crow. Public transportation is often not available and in many areas there are simply no services. The Omnibus Study done in 2004 showed that 44% of all dementia caregivers do not use any type of services. In addition, they spend their own money to take care of the person with dementia.

Currently there are 42,000 West Virginians with Alzheimer's disease and age is the greatest risk factor for developing Alzheimer's. West Virginia has the second highest average age in the nation. 75% of all individuals with Alzheimer's are cared for at home. According to the Statistical Abstract we are the only state that did not experience a natural increase in population, where births outnumber death. We have the highest death rate in the nation. Our caregivers are aging rapidly.

A study done by the University of Pittsburgh two years ago found that caregivers are 63% more likely to die before those who are not caregivers.

Can we as a nation, can we as a state, afford to ignore not only the oncoming crisis of the 16 million Americans who will have Alzheimer's disease by mid century, but also ignore the plight of these caregivers?

One very simple service we can offer is respite care. Respite care for these families will allow them to keep their loved ones at home longer. Respite Care for families will allow caregivers to see to their own healthcare needs, get a much needed break and give them a refreshed ability to care and to cope.

In the year 2000, Medicaid spent an estimated \$18.2 billion on nursing home care for people with Alzheimer's. Enabling caregivers to keep their loved ones at home longer may ease the burden on Medicaid.

Perusing the internet recently, I discovered information about rural initiatives on the USDA website. The United States currently offers \$22.8 million dollars in available grants for renewable energy projects in rural areas. While I realize this is to decrease our dependence on foreign oil, it sparked a question... what are we providing to renew the energy of caregivers?

In the past few years we have seen an outpouring of disaster relief efforts, 9-11, hurricanes and the Tsunami have spurred efforts to assist families dealing with these disasters. Last year \$45 million dollars was raised for the Red Cross. In January of this year, the President signed into law HR 241 which allows for tax benefits for donations to Tsunami relief. American are historically generous when a disaster hits. Well, a disaster is on its way.

Just a few weeks ago, at a conference in Washington DC, I met Tracy. She is 40 years old and was diagnosed with Alzheimer's two years ago. She and her husband declared bankruptcy last year after becoming mired in the medical bills resulting from efforts to diagnose her problem. Doctors presumed she was much too young to have Alzheimer's. The codes the physicians had used classified the many tests as neuro-psychological rather than simply neurological, therefore her insurance company refused to pay. I met her husband and her 10 year old son. Tracy commented that she was fighting her Alzheimer's with everything she had, but she was particularly alarmed at the mortality rate for caregivers and was very worried about her husband and the stress he was experiencing. She commented that "my son and I can't do without him"

I respectfully request that you heed the warning of this coming disaster. The onslaught of Alzheimer's as baby boomers age, will overwhelm us. It will bankrupt our healthcare system. There is much to be done including more research to find a cure but today, I ask that you

support and urge the passage of the Ronald Reagan Breakthrough Act that was reintroduced in Congress this spring. This legislation will provide increased research funding, funds for respite care and a tax credit for families caring for a loved one with Alzheimer's disease.

There are hundreds of thousands of caregivers like Louise and Tracy's husband and as Tracy said, we can't do without them.

Thank you.